RESEARCH ARTICLE doi: 10.5543/khd.2017.39306 ARASTIRMA

# Determining the Care Burden and Anxiety Levels of Caregivers of Elderly Patients with Heart Failure

Kalp Yetersizliği Olan Yaşlı Hastaya Bakım Verenlerin Bakım Yükü ve Anksiyete Düzeylerinin Belirlenmesi

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#### **ABSTRACT**

**Objective:** The aim of this descriptive study is to determine the care burden and anxiety levels of caregivers of elderly patients with heart failure.

**Methods:** This descriptive study was conducted at İnönü University Turgut Özal Medical Centre (Cardiology) between June 2013 and July 2015. The sample consisted of 165 individuals taking care of elderly patients, aged 65 and over, who were hospitalised due to the diagnosis of heart failure. The data were collected by using the Introductory Questionnaire for Caregivers and Elderly Patients, which was prepared by the researcher, as well as the Burden Interview (BI) and State-Trait Anxiety Inventory (STAI).

**Results:** This research determined that most of the caregivers were female, married and satisfied with caregiving; that there was a positive correlation between care burden and trait anxiety; and that, as the care burden increased, the trait anxiety score increased.

**Conclusion:** In the study, it was determined that elderly patients were mainly cared for by their daughters and that there was a positive correlation between the care burden and anxiety. Caregivers are to be supported physically, psychologically, socially and spiritually in order to decrease their anxiety and care burden.

Keywords: Heart Failure; Care Burden; Anxiety.

#### ÖZET

**Amaç:** Bu çalışmanın amacı kalp yetersizliği olan yaşlı hastaya bakım verenlerin bakım yükü ve anksiyete düzeylerinin belirlenmektir.

Yöntemler: Bu araştırma, İnönü Üniversitesi Turgut Özal Tıp Merkezi Kardiyoloji servisinde Haziran 2013-Temmuz 2015 tarihleri arasında yapıldı. Örneklemi Kardiyoloji Servis'inde kalp yetersizliği tanısıyla yatmakta olan 65 yaş ve üzeri yaşlı hastaya bakım veren, 165 bakım veren oluşturdu. Verilerin toplanmasında araştırmacı tarafından hazırlanan Bakım Veren Bireyi ve Yaşlı Hatayı Tanıtıcı Anket Formu, Bakım Yükü Ölçeği (BYÖ) ve Durumluk Sürekli Kaygı Envanteri (STAI) kullanıldı.

**Bulgular:** Araştırmada bakım verenlerin çoğunluğunun kadın, evli ve bakım vermekten memnun oldukları, bakım yükü ile sürekli anksiyete arasında pozitif ilişki olduğu, bakım yükü arttıkça sürekli anksiyetenin de arttığı belirlendi.

**Sonuç:** Araştırmada yaşlı hastalara çoğunlukla kız evlatların bakım verdikleri ve bakım yükü ve anksiyete arasında pozitif ilişki olduğu saptandı. Bakım verenlerin yaşadığı anksiyete ve bakım yükünü azaltmak için fiziksel, psikolojik, sosyal ve spiritüel yönlerden desteklenmesi önerilebilir.

Anahtar Kelimeler: Kalp Yetersizliği; Bakım Yükü; Anksiyete.

#### **INTRODUCTION**

Today, the incidence rate of heart failure (HF) is gradually increasing in both developed and developing countries due to the aging societies and prevention of deaths by advancing technology. HF causes a high rate of morbidity and mortality, especially in elderly people. [1,2] More than 2.4 million patients are hospitalised, and approximately 300.000 patients pass away due to HF every year. [3]

There are more than 23 million patients with heart failure around the world. [4] In Turkey, on the other hand, the prevalence of heart failure in the general population varies between 0.3-2%, and HF is encountered at the rates of 3-5% among individuals older than 65 years and 25% among individuals older than 75 years.[1]

Aging brings along a number of geriatric problems, which mainly involve care and caregiver needs. Family members provide care to elderly patients in both Turkey and developed countries. Even though the majority of caregivers within families used to be women, this situation has changed in recent years, with many men becoming caregivers, as well. As the responsibilities of the caregiver increase, caregiving becomes more difficult and imposes a burden on caregivers. <sup>[5,6]</sup>

In their study, Zincir et al. determined that caregivers experienced a high level of care burden and that female caregivers felt a greater burden compared to male caregivers. [7] Heart failure requires a long process of care from its diagnosis and places a heavy burden on caregivers by affecting them physically, psychologically, economically, and spiritually.[8] Depressive symptoms are observed in 45% of caregivers of patients with heart failure. [9]

Even though the burden and anxiety levels of caregivers are very important, upon reviewing the literature, a limited number of studies on this subject were determined. For this reason, the determination of care burden and anxiety level is important in planning the nursing approach.

# **METHODS**

# Study design and sample

This descriptive study was conducted at Turgut Özal Medical Centre (Cardiology) between June 2013 and July 2015. The population of the study consisted of 290 individuals taking care of elderly patients aged 65 and over, who were hospitalised due to the diagnosis

of heart failure either before their hospitalisation or at the hospital. The sample group, on the other hand, consisted of 165 individuals taking care of elderly patients aged 65 and over, who were hospitalised due to the diagnosis of heart failure. Its size was calculated according to the sampling formula with a finite population.

Inclusion Criteria:

- Caregiver taking care of the elderly patient at home and at the hospital;
- Caregiver being 18 and older;
- Caregiver being related to the elderly patient;
- Caregiver having no perceiving, hearing or speaking problem;
- Caregiver having no perceiving, hearing or speaking problem;
- Caregiver having no relative who died due to HF before.

#### Data Collection

The data of the study were collected between February and June 2014. The data were collected by using the Introductory Questionnaire for Caregivers and Elderly Patients, which was prepared by the researcher, as well as the Burden Interview (BI) and State-Trait Anxiety Inventory (STAI).

#### Instruments:

Introductory Questionnaire For Caregivers and Elderly Patients

The questionnaire consisted of 15 questions about the descriptive characteristics of caregivers and five questions about the descriptive characteristics of elderly patients.

## **Burden Interview (BI)**

The interview was developed by Zarit et al. in 1985. The clinically adapted version, valid and reliable to scale in Turkey, was conducted by Özer et al. (2012) and includes 18 questions. The score interval of the scale varies between 0 and 72, and the increase in the scale score also increases the care burden. The Cronbach's alpha coefficient of the scale varies between 0.81 and 0.83. [10] In this study, the Cronbach's alpha coefficient was determined as 0.94.

## State-Trait Anxiety Inventory (STAI)

The study of inventory, with Turkish validity and reliability, was conducted by Öner and Le Compte

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in 1983. The inventory consists of 40 items (20 items in the State Anxiety Inventory and 20 items in the Trait Anxiety Inventory). The feelings or behaviours expressed in the items of the State Anxiety Inventory are answered by marking one of the following options: (1) never, (2) a little, (3) much and (4) entirely according to the degree of feeling in the situation. On the other hand, the feelings or behaviours expressed in the items of the Trait Anxiety Inventory are answered with the following options: (1) almost never, (2) sometimes, (3) often and (4) almost always, according to their frequency. The Cronbach's alpha coefficient of the inventory was determined between 0.94 and 0.96 for the 'State Anxiety Inventory' and between 0.83 and 0.87 for the 'Trait Anxiety Inventory'. [11] In this study, the Cronbach's alpha coefficient was determined as 0.94 for the 'State Anxiety Inventory' and 0.83 for the 'Trait Anxiety Inventory'.

#### **Ethical Considerations**

A written permission was received from the Malatya Clinical Trials Ethics Committee (2014/06) before the study. After the study, participants were informed about the questionnaires, told that the acquired information would be kept confidential and that study participation would be voluntary, with their verbal consents being received. The study is in accordance with the principles in the Declaration of Helsinki.

## **Data Analysis**

The data obtained from the study were evaluated by using the SPSS 16.0 packaged software. Numbers and percentages were used to assess the data; Independent Samples t-Test, Kruskal Wallis, Mann-Whitney U, and ANOVA were used in comparing the scale, total scores and descriptive characteristics; and a correlation analysis was used to determine the correlation between the mean scores of the Burden Interview and State-Trait Anxiety Inventory. The results were accepted as statistically significant at the confidence interval of 95% and significance level of p<0.05.

# **RESULTS**

Table 1 illustrates the distribution of the caregivers based on their descriptive characteristics. It was determined that the caregivers had an age average of  $45.08 \pm 13.7$  years (18-78): 46.7% were in the age range of 39-59 years, 75.2% were female, 78.8% were married, 52.8% were primary school graduates,

80.6% were unemployed, 69.1% had a social security, 55.2% had a lower income than expense, 69.1% had no chronic disease, 31.5% were daughters of the elderly patients, 84.8% were satisfied with caregiving, and 79.4% provided care for the elderly patient for 1-5 years.

**Table 1.** Descriptive characteristic of caregivers (n:165).

Variables	N	0/0
Age (years)		
18-38	56	33.9
39-59	77	46.7
60 and above	32	19.4
Gender		
Female	124	75.2
Male	41	24.8
Marital status		
Married	130	78.8
Single	35	21.2
<b>Education level</b>		
Illiterate	28	17.0
Primary school	87	52.8
Secondary school	35	21.2
University and above	15	9.0
Occupational status		
Working	32	19.4
Not working	133	80.6
Income		
Less income than	91	55.2
expenses		
Income equal to	74	44.8
expenses		
<b>Chronic Diseases</b>		
Yes	51	30.9
No	114	69.1
Relationship with the		
elderly		
Spouse	36	21.8
Daughter	52	31.5
Son	27	16.4
Grandson	27	16.3
Daughter-in-law	23	14.0
Satisfied with		
caregiving		
Yes	140	84.8
No	25	15.2
Period of giving care		
1-5 years	131	79.4
6-10 years	21	12.7
11 and above years	13	7.9

Table 2 illustrates the distribution of the elderly patients based on their descriptive characteristics. The elderly patients with heart failure had an age average of 72.30±6.17 years. It was determined that 68.5% of the elderly patients were in the age group of 65-74 years, 55.2% were female, 51.5% were married, 60.0% were illiterate, and 70.9% suffered from heart failure for 1-5 years.

**Table 2.** Descriptive characteristic of elderly patients (n:165)

Variables	N	0/0
Age		
65-74	113	68.5
75-84	43	26.0
85 and above	9	5.5
Gender		
Female	91	55.2
Male	74	44.8
Marital status		
Married	85	51.5
Single	80	48.5
<b>Education level</b>		
Illiterate	99	60.0
Primary school	56	34.0
Secondary	10	6.0
school		
<b>Duration of</b>		
illnes		
1-5 years	117	70.9
6 and above	48	29.1
years		
Mean Age*	72.30±6.17	

<sup>\*</sup>Means±SD:Means±Standart Deviation

When examining the comparison of descriptive characteristics and BI mean scores of the caregivers, it was found that the care burden was higher among individuals aged 60 and over, which was followed by the age group of 39-59 years; the difference between the groups was statistically significant (p<0.05). When examining the anxiety mean scores in terms of age groups, it was determined that the state anxiety score was higher in the age group of 18-38 years compared to the other groups, but the difference between the groups was statistically insignificant (p>0.05); whereas, the trait anxiety score was higher in the age group of 60 and over compared to the other age groups, and the difference between the groups was statistically significant

(p<0.05). When examining the care burden mean scores in terms of gender of the caregivers, it was found that care burden was higher in women than men, but the difference between the groups was statistically insignificant (p>0.05). When examining the anxiety mean scores in terms of gender, it was determined that men had higher mean scores in both state and trait anxiety than women, but the difference between the groups was statistically insignificant (p>0.05). When examining the care burden mean scores in terms of marital status, it was determined that the care burden mean scores were in married individuals than individuals, but the difference between the groups was statistically insignificant (p>0.05). When examining the anxiety mean scores in terms of marital status, it was found that, while single individuals had higher state anxiety mean score, married individuals had higher trait anxiety mean scores; the difference between the groups was statistically insignificant (p>0.05). It was determined that unemployed caregivers had a higher care burden compared to employed caregivers, and the difference between the groups was statistically significant (p<0.05). When examining the anxiety mean scores in terms of employment status, it was found that unemployed caregivers had higher mean scores in both state and trait anxiety, but the difference between the groups was statistically insignificant (p>0.05). When examining the care burden mean scores in terms of the affinity of the caregivers to the elderly patients, it was determined that the care burden was higher in daughter-in-laws compared to the others, which was followed by spouses; the difference between the groups was statistically significant (p<0.05). When examining the anxiety mean scores in terms of the affinity of the caregivers to the elderly patients, it was found that spouses and sons had higher mean scores in both state and trait anxiety compared to the others, and there was a statistically significant difference between the affinity and the anxiety score (p<0.05). The care burden was higher in those who were not satisfied with caregiving, and the difference between the groups was statistically significant (p<0.05). When examining the anxiety mean scores in terms of the state of being satisfied with caregiving, it was found that those who were not satisfied with caregiving had higher mean scores in both state and trait anxiety, and the difference between the groups was significant in trait anxiety (p<0.05) (Table 3).

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**Table 3.** Comparison of mean scores of care burden and state-trait anxiety scale by descriptive characteristics of

caregivers.

				State Trait Anxiety Scale			
Variables	n	BYÖ	p-value	State Anxiety		Trait Anxiety	
		X±SD		X±SD	p-value	X±SD	p-value
Age							
18-38	56	34.76±14.78	3.90	43.01±3.23	0.69	48.58±3.95	3.94
39-59	77	38.09±19.96	p: .022a	42.31±3.66	p: .503a	49.84±4.71	p: .021a
60 and above	32	46.21±21.05	-	42.87±4.08	-	51.25±3.95	-
Gender							
Female	124	39.83±19.03	1.540	42.41±3.67	-1.552	49.49±4.27	1.010
Male	41	34.60±18.26	p: .126 <sup>b</sup>	43.41±3.31	p: .123b	50.29±0.74	p: .314 <sup>b</sup>
Marital status							
Evli	130	38.86±19.86	0.420	42.40±3.69	-1.803	49.94±4.52	1.440
Bekar	35	37.34±15.10	p: .675 <sup>b</sup>	43.62±3.10	p: .073b	48.74±3.82	p: .152 <sup>b</sup>
Occupational status							
Working	32	31.09±15.41	-2.519	42.37±3.29	-0.498	48.43±4.28	-1.807
Not working	133	40.33±19.30	p: .013 <sup>b</sup>	42.72±3.68	p: .619 <sup>b</sup>	49.99±4.39	p: .073b
Relationship with th							
eelderly	36	43.66±22.28	14.460	43.25±3.95	14.460	51.00±3.82	9.554
Spouse	52	38.13±19.15	p: .006 <sup>c</sup>	42.67±3.39	p: .168 <sup>c</sup>	49.84±4.11	p: .049°
Daughter	27	33.44±18.29	P000	43.18±3.88	P100	50.48±5.20	P. 1017
Son	_,	30.11210.27		10.10_0.00		20.1020.20	
Grandson	27	30.77±14.84		42.88±2.63		48.51±4.00	
Daughter-in-law	23	46.52±12.59		40.82±3.82		47.73±4.65	
Satisfied with caregiving							
Yes	140	35.35±16.95	747.500	42.73±3.46	1623.500	49.27±4.08	1228.000
No	25	56.40±19.76	p: .000d	42.73±3.40 42.24±4.34	p: .563d	52.04±5.39	p: .017 <sup>d</sup>
	20	JU. TU-17.7 U	P000	12,2717,07	p505	52.04±5.57	P017

a: One Way Anova b: İndependent t testi c: Kruskal- Wallis d: Minn-Whitney U

There was a positive correlation between care burden and trait anxiety, and as the care burden increased, the trait anxiety score increased. Additionally, there was a positive correlation between the state-trait anxieties of the caregivers, and as the level of state anxiety increased, the level of trait anxiety increased, as well (Table 4).

**Table 4.** Correlation between caregiver burden scale and state-trait anxiety (n:165)

	Caregiver Burden Scale		Trait Anxiety		
	r	p	r	p	
State Anxiety	-0.020	0.800	0.202**	0.009	
Trait Anxiety	0.166*	0.033			

<sup>\*</sup>p<0.05 \*\*p<0.01

## **DISCUSSION**

In the study, it was determined that the caregivers who were 60 and over had a higher care burden, and the difference between the groups was statistically significant. In a study conducted by Saunders, it was found that the care burden increased with increasing age. <sup>[12]</sup> It is thought that health problems increase with old age and, therefore, caregiving becomes difficult.

In the study, it was determined that the caregivers aged between 18-38 years had a higher level of state anxiety compared to the others, but the difference between the groups was statistically insignificant. The trait anxiety score was higher in individuals aged 60 and over, and the difference between the groups was statistically significant (Table 4). In their study, Carter et al. determined that, with increasing age, the life quality of the caregivers increased, and they experienced fewer psychological problems and less anxiety.[13] In their study, Chung et al. determined that, as the age of caregivers increased, the depressive symptoms decreased.[14] It could be asserted that caregiving became challenging with increasing age, and caregivers experienced uncertainty regarding the future, which increased the level of anxiety.

As a result of the study, it was found that female caregivers had a higher care burden when compared to male caregivers, which was statistically insignificant. This was also confirmed by the study conducted by Şahin.<sup>[15]</sup> The fact that women experienced a higher care burden than men could be associated with them not efficiently coping with the function of caregiving, having responsibilities other than caregiving and not having any sufficient or efficient support systems.

In the study, it was determined that male caregivers had higher mean scores in both state and trait anxiety compared to female caregivers. In their study, Schulz et al. found that women experienced depressive symptoms two times higher than men. [16] In our society, the task of caregiving is mainly fulfilled by women. As men undertake fewer tasks in this area, they may experience a greater anxiety due to the concern for failure.

In the study, it was determined that married caregivers had a higher care burden compared to single caregivers, but the difference between the groups was statistically insignificant. In their study, Dunbar et al. determined that married caregivers had a higher care burden compared to single

caregivers. [17] It was thought that married caregivers experienced a higher care burden, as they had greater responsibilities in daily life compared to single caregivers (working, housework, child care, etc.).

In the study, it was determined that unemployed caregivers had a higher care burden compared to employed caregivers, and the difference between the groups was statistically significant. In their study, Zaybak et al. determined that unemployed caregivers had a higher care burden than employed caregivers. [18] As unemployed caregivers spent a longer time each day taking care of elderly patients, they may have experienced a higher care burden than employed caregivers.

It was determined that unemployed caregivers had higher scores in both state and trait anxiety compared to employed caregivers. In their study, Park et al. reported that unemployed caregivers had a lower quality of life, a higher care burden, anxiety and depression during the caregiving. [19] It was considered that unemployed caregivers experienced anxiety and depression from their financial trouble due to unemployment.

As a result of the study, it was specified that daughter-in-law caregivers had a higher care burden compared to the others, and the difference between the groups was statistically significant. In patriarchal societies, the wives of sons (in other words, the daughter-in-laws) are responsible for meeting all the needs of the elderly people. [20] It is thought that daughter-in-laws who fulfil the task of caregiving due to their husbands experience a higher burden, as they undertake the task of caregiving unwillingly and must balance this task with their household responsibilities.

As a result of the study, it was found that individuals taking care of their spouses had higher scores in both state and trait anxiety, and while the difference between the groups in terms of the state anxiety was insignificant, the difference was significant in terms of the trait anxiety. It is thought that the advanced age of the caregivers of elderly patients is effective upon the increase in care burden and that the fear of losing elderly patients is effective upon the increase in anxiety levels.

In the study, those who were not satisfied with caregiving had a higher care burden compared to those who were satisfied with caregiving, and the difference between the groups was statistically significant. The concept of satisfaction with care

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signifies the positive approach and effect of caregivers, regarding individuals to whom they are liable to provide care.<sup>[21]</sup> Since individuals who take on the role of caregiving unwillingly have difficulty adapting to this role, they may experience a higher care burden.

In the study, it was determined that those who were not satisfied with caregiving had higher trait anxiety scores, and the difference between the groups was statistically significant. In their study, Prasad and Rani determined that the advanced age and lower income of caregivers had a negative effect upon satisfaction with care, and this condition increased the anxiety and stress levels.<sup>[22]</sup> It was thought that caregivers who did not fulfil the task of caregiving willingly experienced anxiety, as they had a greater difficulty and perceived everything negatively.

As a result of the study, it was determined that there was a positive correlation between the care burden and trait anxiety, and as the care burden increased, the trait anxiety also increased. Additionally, there was a positive correlation between the state anxiety and trait anxiety of the caregivers. In their study, Özyeşil et al. determined a positive, significant correlation between the care burden and state-trait anxiety.<sup>[23]</sup> It was thought that, since caregiving may have a negative effect upon the psychological health and well-being of caregivers, the anxiety level of caregivers increased.

# **CONCLUSION**

In the study, it was determined that care for elderly patients was mainly provided by their daughters, and there was a positive correlation between the care burden and anxiety. In order to decrease the burden of caregivers, it is recommended for medical teams and nurses to provide training and consultancy services aimed at primary problems; and for caregivers to be supported physically, psychologically, socially and spiritually in order to decrease their anxiety and care burden.

# Limitations of the study

The caregivers included in the study were selected by using the improbable random sampling method, which constitutes the limitation of this study. Thus, the results could be generalised to the group included in the study.

#### Conflict of interest

No conflict of interest has been declared by the authors.

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